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ABSTRACT

This two-volume set containing guidelines and a handbook is intended for persons monitoring the quality of community residences for retarded individuals. The guidelines document begins with a monitoring review worksheet which elicits information in the following categories: human, civil, and legal rights; environment; use of community resources; commitment to personal growth; staff; and personal relationships. The questions in each category are preceded by a brief statement of the issue. A bibliography of residential monitoring instruments completes the guidelines. The handbook contains resource material for monitors, including information on the following: qualifications of a residential service monitor; residential services planning and basic principles; principles for the operation of community residential services; criteria for selecting a residence; some major residential models; the principle of normalization; the community imperative; and common negative practices in community residences. A bibliography on community residences and residential quality contains 32 items. Appended are: the certificate of volunteer monitor training completion and confidentiality agreement; a sample volunteer job description; a list of community resources; potential staff training topics; a sample schedule for a training workshop; a proposed procedure for filing monitoring reports; an outline of a monitoring report; and various sample affiliation agreements. (DB)

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MONITORING COMMUNITY RESIDENCES

GUIDELINES

Developed by

ARC-OHIO

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Material in this document is based on the extensive work of Wolf Wolfensberger, Ph.D. His influence is gratefully acknowledged.

Dr. 'Hank' Bersani, Jr. was selected as the 1985 Joseph P. Kennedy, Jr. Foundation Fellow in Public Policy Leadership and has been assigned to Senator John Chafee's (R-R.I.) office in Washington, D.C. to assist with S 873 - the Community and Family Living Amendments Act of 1985.

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INFORMATIONAL NOTES

Monitoring Community Residences: Guidelines is part of a two volume set produced and published by the Association for Retarded Citizens-Ohio (ARC-Ohio). These guidelines are designed to be used in conjunction with the companion volume: Monitoring Community Residences: Handbook. Inquiries about both volumes may be directed to the address below.

In addition to the Guidelines and the Handbook, ARC-Ohio has developed a day-long training session to prepare potential monitors in the various aspects of monitoring community residences. Arrangements for training sessions may be made through the ARC-Ohio offices.

Please direct all inquiries about these publications or the ARC-Ohio monitoring project to either:

ARC-Ohio
360 South Third St., Suite 101
Columbus, Ohio 43215
(614) 228-4412

or

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123 College Place
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(315) 423-3851

HOW TO USE THESE GUIDELINES

The Monitoring Community Residences: Guidelines are just that.. a guideline. It was developed to be used by you, in conjunction with your handbook, as you see fit. Basically, the guidelines are a list of questions to guide your inquiry during the monitoring visit.

These questions may be answered in many ways: Some may be answered by directly asking administrators, staff, residents, parents, or even neighbors. Others may be answered by direct observation, by reviewing written materials, or by phrasing your own questions that will elicit the same answers.

The questions in this guideline should serve only as a guide to your information gathering. Remember, we cannot possibly anticipate every issue that might come up. You may need to explore more specific issues in more detail than can possibly be outlined in the guidelines.

Before you go out to visit a residence, you should be familiar with the major areas and individual questions. It is essential to plan out in advance how you will ask questions, and where you expect to find the answers.

Whenever possible, write notes as you go. By the end of the day you will have forgotten information you thought was unforgettable just a few hours before. Details are important!

Monitoring requires time! Time to prepare, time to visit, time to reflect, time to write a report and time to follow-up. Don't underestimate the time that will be required. We estimate each visit will require eight (8) hours (4 on-site and 4 writing the report) however, this could vary widely.

PLEASE NOTE: This is not a 'check list' approach to monitoring. The Guidelines ask questions which need to be answered. Some answers may be a 'yes' or 'no', but more often answers will be several sentences long. For infmation on formulating a report, see the Handbook.

MONITORING REVIEW COVER SHEET
BASIC BACKGROUND INFORMATION

Name and Address of Residence:

Name of Contact Person:

Phone Number of Contact Person: ( )

What is the operating agency:

Monitor's Name:
Contact Person:
Address:

Phone: ( )

Day and Date of Visit:

Time of Observation: From: To:

Current Number of Individuals Living There:

Age Range of Individuals:

Are any of the individuals who live there said to have any other disabilities in addition to mental retardation? If so, what?

As described by staff, what levels of mental retardation are the individuals said to have?

How many individuals is the building licensed to hold?

Number of bedrooms?

How long has the home been open?

What type of certificate does the home hold?

What funding sources are used?

RIGHTS

ISSUE: Human, civil, and legal rights are held by all persons, and are not forfeited merely by living in a community residence. Service providers are obligated to respect and protect all aspects of the rights of the people who live there. In addition, residential services have added obligations to teach people about their rights and to assist them in the daily exercise of their full range of rights.

QUESTIONS:

1. How much freedom and encouragement do the people who live here have to decorate their personal spaces, to choose their roommate, to determine their own schedules and activities? Do any restrictions in these areas seem inappropriate for the person's age and level of ability?

2. What procedures are used for house security? Who has keys (residents, staff, administrators)? When are doors locked/unlocked?

3. What procedures are used to keep the people who live here safe from fire and other hazards?

4. Are the people who live there restricted from/or given access to smoking, drinking, sexual activity, birth control, etc.? Is access to food restricted

by staff as a means of control or behavior modification?

5. Are the people who live here free to come and go as they wish?

6. Are there any restrictions on people, such as rules regarding visitors, eating, curfew, etc.? Are they individualized or applied equally to everyone who lives here?

7. Is there a procedure in effect to regulate visits of friends and relatives? If so, how does it work? Do these procedures detract from the home-like quality of the residence?

8. Does the program have a formal, written policy regarding individual rights?

9. Are the people served and their families systematically informed of their full range of legal, civil, and human rights? In writing? (Ask for copies)

10. Do staff encourage the people served to exercise their full range of rights (voting, use of mail, and telephones)?

11. To what extent do the people served determine their own lives?

12. Do formal, written procedures exist for the people being served, families, advocates, etc. to resolve grievances against the staff, or programs? Is there a provision for anonymity? Is there follow up?

Ask for a description of any recent grievance cases and their resolutions.

13. Do the people who live here have their own governance group, council or government? If so, how does it function? If not, why not?

14. Are there some rules that are applied to everyone which some people could better live without?

15. Do any restrictions or regulations seem inappropriate for the person's age and level of ability?

16. Could the lives of some people be improved by changing some rules? How? Whenever possible, specify which person (or people) could benefit from changes in which community).

ENVIRONMENT

ISSUE: First and foremost, a community residence is a home. It's function as a 'program', 'service' or 'agency' is clearly secondary. Efforts must be made to create a physical and social environment which is 'home-like', comfortable, and which asserts the humanity of the people who live there. The residence should not draw any undue attention to the location or the people who live there. The home should blend in with the rest of the neighborhood.

QUESTIONS:

LOCATION

1. Is the home situated in a residential neighborhood, or is it isolated in a non-residential location?

2. Is the residence located so that it is accessible to public transportation? Can people easily get to the house to visit? Can the residents easily get from the house to shopping centers and public facilities (walking, bus, taxi) or is the house isolated due to poor transportation options?

3. Is the home located in a neighborhood that is 'undesirable' due to a high crime rate or poor services?

4. Is the home located in a neighborhood where there is excessive congregation of other people with special

needs?

5. Is the home located close to a variety of relevant community resources and services? (see list of community resources in HAND-BOOK appendix).

BUILDING EXTERIOR

1. Does the residence look like a home? Does it look like the other homes on the block, or does the building stand out as odd, drawing undue attention to the residents?

2. Is the building well kept up? Is the yard maintained in a way to invite visitors, or does the exterior of the building convey an image of isolation and separation from even close neighbors (such as an excessive amount of fencing).

3. From the outside, can you tell this is a 'group-home?' If so, what could be done to change this?

BUILDING INTERIOR

1. To what extent are internal aspects of the home (furnishings, decorations, etc.) appropriate to the age of the people served in the building?

2. Is the residence comfortable and home-like? If you lived there, would you feel comfortable most of the time (consider the number of residents)?

3. Do the decorations and furnishings reflect the

actual ages of the residents (adult furnishings for adults, child-like furnishings for children), or is the home decorated in a way that encourages us to think about the residents as younger and less mature than they really are?

4. How comfortable are the 'community use' rooms (eg. living room, bathrooms, dining room, game room)? Is the amount of space sufficient for the number of people who live there and their individual needs?

5. Is the building divided into recognizable, functional areas as in other homes (does the living room look like a living room, a kitchen like a kitchen, etc.)? Or have rooms been used in odd or unusual ways?

6. If you wanted to be alone, or with a friend, would you have a place to go?

7. Are areas properly lit, heated, cooled, and furnished for their purpose (a game room should be different than a bedroom).

8. In general, are the furnishings of the sort that we expect to find in ordinary homes, or are they so odd as to draw undue attention to the residents, or lead a visitor to wonder about the true nature of the home (for example, does an industrial stove and dishwasher make the atmosphere of a hospital rather than a home)?

9. Do things work (appliances, etc.) or is there an ex-

cessive level of disrepair?

10. Is the home barrier free? Could a person who uses a wheelchair live there?

SOCIAL ENVIRONMENT

1. How do staff talk to and about the people served? Do staff talk to or about adults as though they are children (consider tones of voice, as well as what is said) or does the language of staff convey a sense of respect for people as valued individuals?

2. To what extent are the people served referred to by labels, such as "the Downs child", or "the wheelchair person"?

3. What is the social relationship between staff and the people who live there? Are they friends sharing a home, parents and children, or staff and clients?

USE OF COMMUNITY RESOURCES

ISSUE: Although living near resources is desirable, it is even more important that those resources actually be used. The people living in a community residence must have systematic opportunities to use community resources on a regular basis. Resource use should be in small groups (1 or 2) whenever possible. Each individual should have experienced a variety of community experiences appropriate to his/her age and interest. The residential provider is required to demonstrate a commitment to the normalizing use of community resources and community participation for all people who live in the home. Community resources must be used on a consistent basis.

QUESTIONS:

1. Do the people served in the home have regular access to a variety of resources and services in the community (bank, churches, shops, etc.)? (see community resource list in Appendix of Handbook).

2. When community resources are used, do people go out in small groups, or do they always go everywhere as a unit?

3. To what extent do staff promote direct, personal contact between people served and the general public?

4. Are trips to use community resources systematic,

regular, and thought out, or are they sporatic and 'hit-or-miss' in nature?

5. When people use community resources, are they provided an appropriate level of support, not too much and not too little?

6. Does the program actively teach the people who live there to use community resources? Does the majority of the teaching take place in the community?

7. Do the IHP's (Individual Habilitation Plans) reflect specific goals about the use of community resources?

8. Are generic community organizations (scouts, weight-watchers, etc.) used in the community as others use them?

9. Are friends, neighbors, and community service groups used as resources to build personal relationships?

10. How could people's lives be improved by changing the way community resources are used?

11. In what ways could the program make better use of the community as a resource for skill learning and social interaction?

COMMITMENT TO PERSONAL GROWTH

ISSUE: In addition to a place to live, a community residence must provide needed supervision and support in an environment which also provides opportunities for personal growth and development through a variety of experiences. By assuming the responsibility to provide a residential service, an agency, and its staff also accept the obligation to provide a diverse range of learning experiences. These experiences must include a normative amount of exposure to reasonable level of risks. Learning occurs in an environment with manageable failures, and meaningful successes. This commitment to personal growth must include appropriate use of current teaching technologies and adaptive equipment and devices.

QUESTIONS:

1. Do the program and staff demonstrate an active commitment to increase the skills and competencies of the people served?

2. How much time is spent daily in active, organized learning (in the home or in the community)?

3. Are there aspects of the physical environment that unnecessarily limit the opportunity to experience and learn from reasonable physical risks and growth challenges? (Example: shatterproof glass, heavy duty furniture, locked areas)

4. Are there aspects of the program (rules, procedures) that unnecessarily limit the opportunity to experience reasonable social risks and growth challenges? (Example: misuse/overuse of drugs, excessive curfew, inappropriate restrictions on use of appliances, rules needed by some, but applied to all, especially if used as a substitute for a reasonable number of qualified staff).

5. Does each person served have an up-to-date, complete IHP (Individual Habilitation Plan) which addresses all major aspects of his/her needs. (Ask to see copies of IHP's with names removed).

6. Do program plans contain positive statements about each person, statements of ability, as well as descriptions of disability?

7. What opportunities for personal growth and development are currently being overlooked? What teaching/learning experiences are skipped for expediency?

8. To what extent do the grooming, dress and mannerisms of the people served accurately reflect their ages? Are staff actively encouraging 'age-appropriateness' in these aspects, especially for adults?

9. Are the daily schedules of the people served similar to routines followed by non-handicapped peers? Do people engage in activities that are typical for people of their ages? (Example: times of meals, rising, bedtime, etc.)

10. Are the personal possessions and space of the people

served appropriate to their ages? To what extent do staff encourage this? The older people are, the more possessions and space they usually have. Could you fit your possessions in the space of one of the people living here?

11. To what extent do staff recognize and respect the social/sexual needs of the people they serve? Are staff encouraging social/sexual behavior that is appropriate to the person's age? Is there a formal program in place to help people understand their sexual and emotional needs, and to encourage socially acceptable behavior?

12. What kinds of teaching techniques and special equipment are used? Are they appropriate for the people who live there?

13. If there was more money available, would additional equipment be purchased which could promote learning or personal independence?

14. How could the program change to offer the people who live there a greater variety of meaningful, challenging life experiences?

STAFF

ISSUE: Direct care staff are the individuals who actually provide the service received by the people who live in the residence. Because staff may care for people whose needs are quite challenging, they must be well trained, well supported, and well supervised. The number and type of staff on duty at any given time should reflect the needs of the residents, the number of people being served, and the activities associated with the time of day.

QUESTIONS:

1. What is the total number of staff working at the residence? Part-time _____ Full-time _____

2. On an average day how many of these staff would be working:

   in morning___ in afternoon___ in evening___
   over night____

3. What kinds of experience and backgrounds do staff have prior to employment?

4. How many of the staff have previously worked in either a residential and/or mental retardation setting before?

5. What are the minimal qualifications to be

hired? Do any current staff fail to meet this standard? Why?

6. How many staff have quit or had to be fired recently (in the last month, six months, year)? What are the procedures for staff dismissal?

7. Does formal staff orientation/training/programing exist? What amount (number of hours) of pre-service orientation/inservice training do most staff get? (see sample list of staff training topics in Handbook Appendix)

8. Once hired, does staff receive in-service training on a regular basis? How often? How much?

9. How much of the staff training is conducted by the agency, and how much is contracted from other agencies or groups?

10. How extensive is the list of topics covered in the pre-service and in-service training? (compare to list of sample staff training in handbook).

11. Do staff seem competent, motivated, concerned, and interested in their work, or are they just "doing a job"?

12. What are the qualifications and experience of supervisors? Are the qualifications directly relevant to their current position?

13. Are supervisors involved on a daily basis with the

people who live there? How much of their time is spent in 'hands-on', direct contact?

14. When are supervisors present (days, hours)?

15. What is the administrative chain of command? Is it clear to staff, the people who live there, family members, and advocates? Is a written table of organization available?

16. Do staff feel competent and confident in their jobs?

17. Is there a strong sense of cooperation among staff members and the administration? Do they share the same goals, visions, and sense of purpose?

18. How could the program be improved by changes in staff hiring, training, supervision, etc.?

PERSONAL RELATIONSHIPS

ISSUE: Living in the community is a right, and it can provide a better learning/living environment. Ultimately, the development of strong personal relationships is essential. People who are served in residences should have a variety of social and personal relationships with family members, personal friends, and the general public. The residence must systematically encourage these relationships.

QUESTIONS:

1. How many of the people who live here have families? Do these people have any regular contact with their families (phone calls, letters, visits in the residence, visits out of the residence?)

2. How many of the people who live in the residence have specific friends from school or work. Do they ever get together away from the school or work setting?

3. How many of the neighbors come to visit on a regular basis? Do they visit more with staff, or with the people who live in the home?

4. How many of the people who live here have a personal 'advocate' or friend from the community? How often do they go out together?

5. Are any of the people who live here married, engaged, or dating a particular companion.

6. Are people who live here known by name by neighbors, neighborhood shopkeepers, etc.

7. Does the staff make efforts to encourage ongoing social relationships (not just infrequent contact) between people who live here and members of the community at large?

8. What added efforts could be made by staff to establish and sustain personal relationships for the people who live here?

BIBLIOGRAPHY OF RESIDENTIAL MONITORING INSTRUMENTS

The following is a partial list of tools available for monitoring community residences. There is a great deal of variety among them in terms of how sophisticated they are, their availability, and their quality. This list is included here for informational purposes only.

In the back of the companion volume, Monitoring Community Residences: Handbook, there is an additional bibliography

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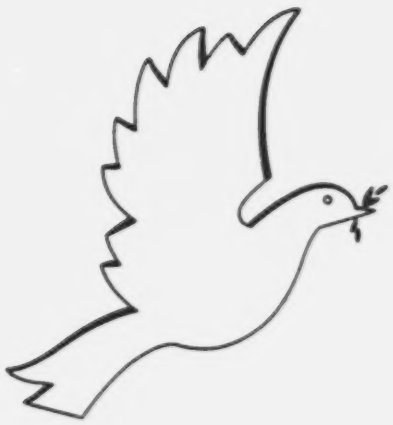

MONITORING COMMUNITY RESIDENCES

HANDBOOK

Developed by

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HOW TO USE THIS HANDBOOK

This document, Monitoring Community Residences: Handbook, is the companion volume to a monitoring tool Monitoring Community Residences: Guidelines. The Guidelines volume is the actual tool to be used in a monitoring evaluation. This Handbook is to be used as a resource book by monitors. It contains information you should read before and after a monitoring visit.

Both the Guidelines and Handbook are designed to be used in conjunction with a day-long training session conducted by ARC-Ohio. Much of the information in the Handbook is related to the training session, and does not stand on its own.

Persons or organizations interested in arranging a monitor training workshop should contact:

ARC-Ohio
360 South Third Street, Suite 101
Columbus, Ohio 43215
(614) 228-4412

Persons interested in further information about this Handbook or the Guidelines should contact:

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123 College Place
Syracuse, N.Y. 13244
(315) 423-3851

All proceeds from the sales of the Guidelines and the Handbook are reserved to support the ARC-Ohio Monitoring Project.

NOTE: Any person who has completed the ARC-Ohio training will be issued a certificate which documents his/her training and in which the monitor signs a confidentiality agreement Appendix A). Service providers may request information about certified monitors from the ARC-Ohio office.

OBJECTIVES OF ARC-OHIO RESIDENTIAL MONITORING PROJECT

The monitoring project developed by the ARC-Ohio is intended to provide a lacking, and very necessary, part of the service delivery system - the monitoring of residential service programs by an independent voluntary group.

Meanings of the word 'monitor' include: 'to watch or check on; to regulate the performance of; to check the quality of.' Monitoring can take many forms and can be done by various groups. The objectives of our program are listed below in order to more fully explain the purpose and benefits of such a project:

--- to assess both the strengths and weaknesses of community residential programs.

--- to provide an independent, external assessment of programs by trained parents and volunteers.

--- to obtain statewide feedback on how services are delivered by providers, and received by individuals who live in community residential facilities.

--- to develop a constructive method by which citizens and service providers can work together to improve the services to persons with mental retardation.

--- to ensure that persons who experience mental retardation have the opportunity to live in community settings which accommodate for their individual needs with a minimum level of restriction.

As parents and volunteers, we often see different things in a program than do professionals. We approach programs with different expectations and concerns. We, therefore, often focus on aspects of programs which may be overlooked by professionals. These observations by parents and volunteers can provide a different and important type of evaluation. These insights may be beneficial to improving services to persons who live in community residences.

INTRODUCTION

The Purpose of Monitoring. It is important for everyone involved in the monitoring process to understand what this monitoring project will and will not do. Such monitoring is not intended to take the place of administrative supervision and case work, it is not intended to take the place of licensure, and certification, and it is not designed to replace regional and statewide supervision by the Department of Mental Retardation/Developmental Disabilities. The presence of a monitoring project by ARC-Ohio does not relieve the Department of Mental Retardation/Developmental Disabilities, caseworkers, or individual providers from the burden of insuring quality in programs themselves. The monitoring project is designed specifically to support and enhance rather than supplant the existing residential safeguards in the state. It is our belief that all of the existing safeguards and monitoring approaches are needed in addition to the private, volunteer, parent and citizen based efforts of ARC-Ohio.

The long term goal of the ARC-Ohio Residential Monitoring Project is to insure and safeguard the human and civil rights of people in community residences. ARC-Ohio is committed to the belief that all of our citizens who experience mental retardation can be supported to live in the community. Such supports include the use of small, home-like settings, carefully developed individual habilitation plans, and staff support to insure success. This monitoring project is one more step to insure that these things occur.

Continued.....

Reasons for Monitoring. Monitoring is a way of increasing the amount of accountability in residential services, from both for profit as well as not for profit provider agencies. Monitoring is a way of alerting everyone involved, agencies, staff, the public, and residents and their families, to the fact that we are concerned about the quality of residential services. Monitoring of this sort that is to be done in this project: independent, external, voluntary monitoring, will not in and of itself guarantee high quality services. We cannot guarantee that programs will change and accept our recommendations. We cannot even guarantee that we will detect all of the problems present in all of the homes that we visit. All that we can hope to do is to be one more check on residential providers, one more set of people who are looking at the situation, one more visit to determine the status within a residence, one more set of concerns being expressed, one more chance to improve the quality of life within the residence.

WHO CAN BE A RESIDENTIAL SERVICE MONITOR

Many people may be interested in being a residential monitor, but may have some reservations. You may ask 'Am I qualified?', 'What will I do?', or 'How much work will it take?'. We would like to answer these questions for you briefly and simply.

--- A residential monitor is a very special person, one with a number of particular qualities.

--- A residential monitor should be familiar with the community and its resources.

--- A residential monitor should be living successfully in the community in his/her own individualized residential setting (your home or apartment <u>does</u> qualify.)

--- A residential monitor should be sensitive to the needs of people, and able to see things from a point of view of empathy with the person being served in the residence.

--- A residential monitor should be committed to high quality residential options for all citizens located in typical housing arrangements in ordinary residential settings.

--- In short, a residential monitor must be concerned, dedicated, sensitive and uniquely 'ordinary'.

--- Who can be a residential monitor?.....<u>YOU</u>!

If you still think you could be a monitor, see the sample monitor volunteer job description. Appendix B.

WHEN A HOUSE IS NOT A HOME

Most community residences are in houses (or apartments). Unfortunately, this does not mean the residence is a home. Many community residences function as 'facilities', which provide 'programs' and 'beds'. To conduct a major evaluation of the quality of a community residence requires some training, a sophisticated assessment tool and a fair amount of time. However, a careful observer, on a guided tour or visit to a residence can quickly evaluate the amount of 'home-ness' and the amount of 'facility-ness' that exists. What follows are some simple guidelines and questions to help you evaluate the home-like quality of any residence you might tour.

First Tour with empathy. Think of the residence, not as a 'place' for 'them', but ask 'what if I lived here?' What would I want?'.

Second Focus on 'what', not 'why'. If you see something wrong (for example, an invasion of privacy), focus on that fact, as experienced by the individual who lives there. There may be a good reason 'why' that is happening (e.g. too few staff). If you are called on to make recommendations you may wish to include the reason 'why' in your proposed solution (hire more staff). However, do not be satisfied with a reason 'why'. ('Oh, well if they don't have enough staff, I guess there is nothing that can be done about it'.)

Third Use your home and your life as a yardstick for comparison. It is unfair to the people who live in a residence to say 'Well, it's better than where they were'. We must ask 'Is it as good as I have now', or 'is it as good as I want for myself and my family?'.

Now! With these 3 points in mind, you are ready to observe, ask, and listen.

Continued.....

LOOK. Are there locks where they need not be (refrigerator, clothes closets?) Are there no locks where there should be (bathrooms, bedrooms, files)?

Do people have the same amount and variety of possessions and personal articles as other people their age? As much as you have?

FEEL. Are the rooms comfortable? The couch? The chairs?

LISTEN. Could you go somewhere for a little peace and quiet?

SMELL. Do you get a scent of home-made dinner on the stove; dessert in the oven; or do you smell institutional cleaners?

TASTE. Would you enjoy the food that is served, or merely tolerate it?

ASK. What are the rules? Are they excessive, or overly restrictive?

INFER. Do the people who live there experience a home with some added support, programming and needed supervision? Or do they experience a program with a few home-like qualities?

ANALYZE. What compromises have been made? In what way do they detract from a home-like atmosphere in the name of budget limitations, programming practices, staff needs, etc.?

REMEMBER. There are 'good' reasons for less than home-like residences. But, there is a difference between a good reason and an unchangeable situation.

ASK YOURSELF. 'If there was an opening tomorrow, would I ask if I could move in?'

Clearly, this is not a sophisticated system for a multi-factor external program analysis. It's not meant to be. But, if you plan to visit a community residence soon, I hope it will give you some insight.

RESIDENTIAL SERVICES PLANNING

BASIC PRINCIPLES

The creating of services should begin by assessing individual needs and the following basic principles to guide planning, development, and implementations:

DEVELOPMENTAL MODEL. Every person, regardless of severity of handicap, has the potential to grow and develop new skills and competencies. This growth and development occurs throughout a person's lifetime, in steps and at individual rates. People with disabilities need extra supports, of various intensities, to aid this growth and development.

PRINCIPLE OF NORMALIZATION. Making available to people with handicaps those patterns and conditions of everyday life that are as close as possible to the norms and patterns of the mainstream of society. This includes promoting warm, positive relationships among clients, between clients and staff and (especially) between clients and non-handicapped peers, and providing challenging programs designed to increase abilities and emphasize similarities, rather than differences, among people.

LEAST RESTRICTIVE ENVIRONMENT. That placement which represents the least removal of a person from the mainstream of society and which exerts no more control over a person's life than is necessary and appropriate for that individual's level of ability.

SUPPORT FOR THE NATURAL HOME. Whenever possible, a person should reside in his/her natural home. However, families of people with handicaps often need extra supports in order to maintain a stable family unit. Service systems have a responsibility to provide such supports to families in order to avoid, or delay, placement outside the home.

RIGHT TO EDUCATION/HABILITATION. All persons with handicaps have a right to those services that will best maximize their potentials for growth and development.

EQUAL JUSTICE. All people with handicaps should be provided with services and supports that allow equal opportunity for growth and development.

RESPECT FOR HUMAN DIGNITY. It is essential that services practice and advocate personal respect for all handicapped people and their right to take normal, reasonable risks.

EFFECTIVENESS AND ECONOMY. Public agencies have a responsibility to provide services in ways that are cost-effective. Services based on the preceeding principles often are also more cost-effective, e.g. as opposed to large congregate service settings.

(By Ron Lawrence, Agency Planner
Butler County Bd. of MR/DD)

PRINCIPLES FOR THE OPERATION OF COMMUNITY RESIDENTIAL SERVICES

(Adapted from NIMR Residential Services Handbook)

Adherance to the principle of normalization and the various practices that it implies.

Physical integration of the setting and the residents into the neighborhood and into the community at large.

Social integration of the residents and the staff into the neighborhood and the community at large.

Commitment to "home-like" scale in terms of the building itself, and the numbers of persons (staff and residents who are involved with the home).

Appropriate level of age group specialization and separation.

Appropriate level of disability specialization and separation.

Adherance to practices, schedules and activities that are "home-like" and normalizing.

A respect for the rights of residents, especially relative to their chronological age.

Appropriate separation of the residence from other aspects of the residents' lives.

Appropriate level of specialization of function of the residence.

Maximized efforts to provide social continuity and physical stability for residents in their contact with staff, family members, neighbors, etc.

Reduction of needless distinctions between staff, residents, family members and the public.

CRITERIA FOR SELECTING A RESIDENCE LOCATION

One of the best ways to 'fix' problems in a community residence is to prevent them during the planning stages. One major factor that can affect residential quality is the location of the home. The following criteria are designed to be used during the planning stage of residential development. However, they may also be used to assess the quality of the location of an existing home.

The location should have a relatively diverse population base, more likely to be accepting of differences.

The neighborhood should have a diversity of residential options (single family homes, apartments, etc.).

The location should have ready access to a variety of commercial establishments and consumer services.

There should be good police and fire protection.

There should be good public transportation.

There should be a variety of opportunities for social contact with non-handicapped persons.

SOME MAJOR RESIDENTIAL MODELS

Too often we equate 'community residence' with 'group home'. Nothing could be less accurate. What follows are descriptions of a dozen different models of community residences.

Family Home:

One or two handicapped persons are accepted into the home of a carefully chosen private family to live, work, and play as a part of that family.

Supervised Group Living:

Three to five children or adults who require daily training, assistance, and supervision. Staff is always on duty and in the residence when residents are in the home, and a program is developed to teach daily living skills (cooking, grocery shopping, washing, ironing, etc.). Living may be in houses or apartments. Residents will be grouped by age and functional ability.

Minimum Supervision Shared Living:

From two to four handicapped persons living together. These people would be semi-independent. They would have more privacy from staff, but staff would drop in or come at scheduled times to help and teach those skills needed by the residents. Staff would not live in the same apartment or house as the people, but would be available when needed and would 'watch over' the residents.

Supervised Apartments:

One or two handicapped persons living in each apartment which are located close together. Staff lives in a separate but close-by apartment and provides immediate supervision, training and support for handicapped persons.

Co-Residency Apartment:

Two or three handicapped and non-handicapped persons who are employed either in workshops or in the community, living together in an apartment and sharing expenses. The non-handicapped person(s) 'helps' the handicapped person(s) with daily living skills. Staff members drop in to consult and guide.

Semi-Independent Apartment:

One to three handicapped persons sharing an apartment. Staff comes by regularly to give help, guidance, and to check to make sure everything is going well. Staff does not necessarily live close by.

Continued.....

Life Sharing:

One or two handicapped persons sharing living quarters (apartment or house) with a non-handicapped person. Non-handicapped person is carefully chosen and is helper and 'role model' for handicapped persons. No formal staff is needed, just the carefully chosen non-handicapped person.

Intensive Medical Care Residence:

Three to five adults or children requiring 24-hour medical treatment for life maintenance (catheters, tube feedings, medication, etc.). Staff on duty around-the-clock when handicapped persons are in the residence.

Temporary (Respite) Care:

Short-term help given to families needing temporary relief from caring for handicapped person, e.g. for a night out, a vacation or in times of emergencies or crises. Help can be given in the family's home by a trained 'sitter', or may be given out of the family's home by staff in another residential setting.

Parent Partnership:

Two or three families with sons/daughters with similar needs contract with county agencies for small-group living, in either houses or apartments. Families work together to choose and find the residence and level of supervision needed. Two to three handicapped persons may live together or with another non-handicapped person. Individual families, instead of the Board of MR/DD, have the larger part of planning this, but with some help. This plan lends itself to many options; for example, use of inherited homes, etc.

Live-In Family Support:

Handicapped person lives at home with natural family, but because of severity of handicap, multi-handicaps, or stress on family, a paid and trained person lives in the home to provide care and training.

Large Facility:

Fifteen or more people with handicaps living together with round-the-clock supervision.

By: Ron Lawrence, Agency Planner
Butler County Bd. of MR/DD

THE PRINCIPLE OF NORMALIZATION

Jack Yates 1978

One may define the ideological goal of the human services in terms of the principle of normalization. This principle can be stated as follows:

> The use of methods and settings which are valued and familiar, to offer each person life conditions and opportunities which are at least as good as those of the average citizen, and as much as possible to enhance and support each person's behavior, status and reputation. (Wolfensberger, 1972)

The principle of normalization implies that every person should have a home. Too often human service systems ask people to live in impersonal institutions or in community facilities which are distinctly unhomelike. Every person should be able to live in a comfortable setting which looks like, feels like, and is a valued home in the community. As much as possible, each person should be able to choose with whom to live, and as much as possible each person should be able to control the conditions of the home environment. Every person should be able to individualize his/her home setting so that the home becomes truly their own.

The principle of normalization implies that adults should be treated as adults. Too often human service systems teach adults to act like children, out of well-meaning but misguided attempts to make life easier for groups who are faced with difficulties. As the people learned to act as they were taught, like children, a vicious cycle was established. It is our responsibility to change this pattern and deal with people on a basis of respect by treating adults as adults, and by helping the people with whom we work to see themselves in an age-appropriate light. Every adult should be encouraged to acquire mature possessions, to build a mature home environment, and to engage in mature activities to the greatest extent possible.

The principle of normalization implies that every person should be challenged and should be enabled to learn. Too often human service systems have held low expectations for people, thus placing a low limit on the learning which could take place. Every person should have a strong, intensive, individualized learning program which will enable that person to gain more and more skills for more and more independence. Every person should be able to make her/his own choices as often as possible, even to take risks in decision making. Instead of providing maximum shelter and protection for a person, we need to encourage growth and development by providing challenges to learning.

Continued.....

The principle of normalization implies that every person should be enabled to participate in the main stream of community life as much as possible. Too often human service systems have isolated people from the rest of society, removing opportunities for learning which would exist among the service consumers and among typical people as well.

Integration into the community will provide models for people who need to learn more social skills, and it will provide a chance for people in general to learn that service consumers are more like other people than different from other people. Every person should be enabled to participate individually or in small groups in all the resources of our society.

To sum up, the essense of the principle of normalization is equality: every person should have the right to equality of opportunity, to share equally in the benefits and difficulties of life in the human community. In our personal interactions and decisions as human service workers, and in our design of programmatic and systemic structures for service provision, we need to plan, act, and teach on that basis.

COMMON MISUNDERSTANDINGS ABOUT NORMALIZATION

Understanding of normalization has suffered in recent years, due to a variety of misleading statements which have been proposed to define or explain it.

FALSE CLAIMS	CLARIFICATION
'Normalization means making people 'normal''.	Normalization does mean that people can often acquire more appropriate behavior and appearances through positive expectations and supporting environments and techniques. However, the principle does not claim to eliminate differences nor to 'cure' handicaps. It is therefore applicable to all people, regardless of the severity or performance of their conditions.
'Normalization means treating people as if they were not handicapped, for example, by exposing them to total integration without supportive services.'	Normalization does not mean dumping people into society without the specialized forms of help they require. It does, however, constantly challenge us to find ways to provide the assistance at times and in settings where valued people are and with procedures which are as typical as possible.
'Normalization denies people the right to be different or individualistic.' or (just the opposite) 'Normalization means that any behavior, appearance, or activity is acceptable because free choice and individual differences are normal.'	Normalization requires that service programs and personal interactions enable and actively encourage people to have behaviors, characteristics, and experiences which are considered familiar or valued in our society. The forms of normative influence which may be used and the normative options which may be selected are diverse and allow for choice and individuality. Furthermore, normalization does not deny a person the right to choose a non-normative option, provided the alternatives and consequences are real and clearly recognized.

COMMON MISUNDERSTANDINGS ABOUT NORMALIZATION - Continued

FALSE CLAIMS	CLARIFICATION
'Normalization means making things 'nice' for handicapped people.' or 'Segrated services are acceptable if they are like similiar services for non-disabled people.'	The primary focus of normalization is on creating social change - on increasing the physical presence and valued participation of handicapped people within the community. Well-meaning attempts to simulate the real world - even its most positive aspects - are inconsistent with the spirit of the principle.
'Normalization is an impractical ideal.'	It is impossible to make progress towards a goal without clearly and systematically defining that goal and the means to reach it. Undoubtedly, normalization as an ideal at times will be in tension with 'reality', but it is important that compromises which must be made be clearly recognized as such.
'Normalization is common sense, new.' or 'Normalization is the same as deinstitutionalization, community services, mainstreaming... We're already doing it.'	Any serious study of the implications of normalization would reveal that our society and our helping services have much to accomplish in order to carry out normalization. Concepts such as 'deinstitutionalization', 'community services', and 'mainstreaming' focus on one service type, location, or technique without specifying the desired quality of life which is the goal. As a result, these concepts are often implemented in ways which are totally inconsistent with normalization.

By: Terri Johnson-Wisconsin
Coalition for Advocacy.

NORMALIZATION

"Normalization means . . . A normal rhythm of the day
You get out of bed in the morning, even if you are
Profoundly retarded and physically handicapped;
You get dressed,
And leave the house for school or work,
You don't stay home;
In the morning you anticipate events,
In the evening you think back on what you have accomplished;
The day is not a monotonous 24 hours with every minute endless.
You eat at normal times of the day and in a normal fashion;
Not just with a spoon, unless you are an infant;
Not in bed, but at a table;
Not early in the afternoon for the convenience of the staff.

Normalization means . . . A normal rhythm of the week.
You live in one place,
Go to work in another,
And participate in leisure activities in yet another.
You anticipate leisure activities on weekends,
And look forward to getting back to school
Or work on Monday.

Normalization means . . . A normal rhythm of the year.
A vacation to break routines of the year.
Seasonal changes bring with them a variety
Of types of food, work, cultural events, sports,
Leisure activities.
Just think . . . We thrive on these seasonal changes!

Normalization means . . . Normal developmental experiences
Of the life cycle:
In childhood, children, but not adults go to summer camps.
In adolescence one is interested in grooming, hairstyles,
Music, boy friends and girl friends.
In adulthood, life is filled with work and responsibilities.
In old age, one has memories to look back on, and can
Enjoy the wisdom of experience.

Normalization means . . . Having a range of choices,
Wishes, and desires respected and considered.
Adults have the freedom to decide
Where they would like to live,
What kind of job they would like to have, and can be best performed.
Whether they would prefer to go bowling with a group,
Instead of staying home to watch television.

Continued.....

Normalization means . . . Living in a world made of two sexes.
Children and adults both develop relationships with
Members of the opposite sex.
Teenagers become interested in having
Boy friends and girl friends.
Adults may fall in love, and decide to marry.

Normalization means . . . The right to normal economic standards.
All of us have basic financial privileges, and responsibility,
Are able to take advantage of
compensatory economic security means,
Such as child allowances, old age pensions, and
Minimum wage regulations.
We should have money to decide how to spend;
On personal luxuries, or necessities.

Normalization means . . . Living in normal housing
Not in a normal large neighborhood with 20, 50, or 100 other people
Because you are retarded,
and not isolated from the rest of the community.
Normal locations and normal size homes will give residents
Better opportunities for successful integration
With their communities."

-- Bengt Nirje

From: National Institute on Mental
Retardation (Canada) Orientation
Manual on Mental Retardation.
(1981 Revised and Expanded version)

NORMALIZATION IN COMMUNITY RESIDENCES: SOME BASIC POINTS

Normalization may mean a lot of things to different people. For the purposes of our Guidelines and this Handbook normalization has some specific meanings.

NORMALIZATION DOES MEAN

A. Every person should have a home.

B. Adults should be treated as adults.

C. Every person should be challenged and should be enabled to learn.

D. Every person should be enabled to participate in the mainstream of community life as much as possible.

E. The essence of normalization is equality.

NORMALIZATION DOES NOT MEAN

A. Making people all the same.

B. Ignoring people's handicaps.

C. The loss of all individual choice.

D. Segregated services are acceptable if they are good.

E. Being either too practical or too ideal.

F. Continuing old practices, but calling them something else.

THE COMMUNITY IMPERATIVE:
A REFUTATION OF ALL ARGUMENTS
IN SUPPORT OF
INSTITUTIONALIZING ANYBODY
BECAUSE OF MENTAL RETARDATION

In the domain of Human Rights:

All people have fundamental moral and constitutional rights.

These rights must not be abrogated merely because a person has a mental or physical disability.

Among these fundamental rights is the right to community living.

In the domain of Educational Programming and Human Service:

All people, as human beings, are inherently valuable.

All people can grow and develop.

All people are entitled to conditions which foster their development.

Such conditions are optimally provided in community settings.

Therefore:

In fulfillment of fundamental human rights and

In securing optimum developmental opportunities,

All people, regardless of the severity of their disabilities, are entitled to community living.

Center on Human Policy
Syracuse University
216 Ostrom Avenue
Syracuse, New York 13210

Accepted by ARC-Ohio as a Policy Statement at the 1984 Annual Convention

COMMON NEGATIVE PRACTICES IN COMMUNITY RESIDENCES

Why is there a need to monitor community residences? What should monitors look for? Sometimes, when we talk about 'the community' versus 'the institution' we assume that all living arrangements in the community are equally good. The fact is that there is a wide range of quality in community programs.

We have identified five common, reocurring problems in community services. Monitors, as well as service providers should be aware of these problems, and work for their elimination. Awareness of a problem is the first step in its solution. In this capacity a monitor is like a smoke alarm -- alerting us to the presence of a problem. Monitors should be alert for the following practices:

--- Senseless dumping of large numbers of persons into unsuitable residential situations to effect a 'number success' by lowering census numbers in targeted institutions.

--- The creation of settings in the community which are of such poor quality, and so saturated with institutional characteristics that they become community back wards. These settings are often little better than traditional institutions.

--- The presence of 'islands of residential services' without developing a rational, systematic approach to residential service provision at the regional or state level. A residential service network is more than a collection of residences.

--- A basic insensitivity to the needs of residents as developing human beings with a full set of human rights, needs, and concerns. Too often the 'group home' is a collection of 'beds' for 'residents' rather than a home for people who live there.

--- Beginning a residential program with inadequate manpower to provide the level of support and supervision needed to be successful. A residence must have full support systems in place before welcoming the first resident.

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APPENDIX A

CERTIFICATE OF VOLUNTEER MONITOR TRAINING COMPLETION
AND CONFIDENTIALITY AGREEMENT

The Association for Retarded Citizens-Ohio hereby certifies that

_____

has completed the minimum hours of training required to begin functioning as a volunteer monitor of residential programs, and agrees with the basic philosophy and principles of said training.

In addition, _____ recognizes the importance of strict confidentiality and hereby agrees to not share any information or impressions obtained during any monitoring, either verbally or written, with anyone outside the specific monitoring team of which he/she is a member.

_____	_____
ARC-Ohio Director	Volunteer Monitor
_____	_____
Date	Date
_____	_____
ARC-Ohio President	Date

APPENDIX B

SAMPLE VOLUNTEER JOB DESCRIPTION: RESIDENTIAL MONITOR

Reports To: Project Coordinator

Purpose of Position: To monitor, as part of a team, community residences for people with mental retardation who have returned to the community from an institutional setting. Particular attention will be given to quality safeguards which ensure that residents' living situations are homelike. Monitors should ask themselves the question: Is this a home I would like someone I care about to live in?

Qualities:

1. Belief that everyone has a right to live in the community with proper supports, regardless of disability.
2. Willingness to commit to the project for at least one year.
3. Able to work as a team member and to submit necessary written documentation.
4. Commitment to monitoring as constructive feedback to providers to improve the quality of life of residents, rather than as a way to "get" providers whose programs are having problems.
5. Completion of training program.
6. Warm, caring, compassionate, and sensitive to needs of people.
7. Diplomatic.
8. An appreciation for the importance of confidentiality.

Responsibilities.

Attend training
1 visit/month
4 sites, 3 x/year
8 hours/visit
responsible for completing written report

APPENDIX C

COMMUNITY RESOURCES

Residences should be located near, and make use of, a wide variety of community resources including:

- banks
- churches
- fast food restaurants
- family restaurants
- laundramat
- park
- movie theatres
- swimming pool
- community center
- bus lines
- grocery stores
- schools
- department stores
- bowling lanes
- service organizations
- library
- variety stores
- museum
- barber/stylists
- specialty stores
- other people

In all cases, the resources used should be appropriate to the chronological age and needs of the individuals. Resources should be used in a way which enhances dignity and supports individuality.

APPENDIX D

POTENTIAL STAFF TRAINING TOPICS

First Aid

Fire and Safety procedures

Administration of medications/Looking for side-effects

Writing and implementing IHP's (Individual Habilitation Plan)

Behavior Management

How to communicate with other agencies and professionals

How to use community services

Overview of residential alternatives

Residents' rights

Acting as an advocate for residents

The principle of normalization: What it is and is not

Human sexuality and mental retardation

Overview of developmental disabilities

Working with parents, guardians, and families

The consumer's perspective: What it's like to live in a group home

Coping with work stress and preventing burn out

Special problems of housekeeping in a large household

Overview of state MR/DD structure

Overview of staff benefits package

Mobility training

Range of Motion Exercises

Sign Language/Alternate Communication

Leisure and Recreation Options

Nutrition, Meal Planning

APPENDIX E

SAMPLE SCHEDULE
FOR A
MONITOR TRAINING WORKSHOP

8:30 Introduction
- Overview of schedule
- Overview of goals for the day
- Overview of monitoring project

9:30 Basic principles, philosophies and goals
- Deinstitutionalization
- Normalization
- ARC-Ohio policies
- Related policy statements

11:30 Overview of residential services
- Common problems/current practice
- Residential Forms, functions, options
- Positive practices

12:30 Lunch

1:00 Review of monitoring Guidelines and Handbook

Rights	Environment
Personal Growth	Resources
Staff	Conclusions

4:00 Creating change
- Suggesting changes
- Feedback to agency
- Writing reports
- Follow-up on recommendations

4:30 Critique Session
- Questions on content
- Comments on process
- Suggestions for changes
- Wrap-Up

APPENDIX F

PROPOSED PROCEDURE FOR FILING MONITORING REPORTS

A. Monitors arrange visit

B. Visit home

C. Monitors ask questions/take notes

D. Monitors meet together and discuss visit
Exit interview with provider - verbal

E. Monitors draft a report

F. Monitors send ARC-Ohio draft report with all notes

G. ARC-Ohio staff person will edit report (using standard reporting form developed for all reports)

H. ARC-Ohio will type final report notes/draft report/final report and will be locked in file

I. Monitors will sign approved final report and return to ARC-Ohio (no copies are to be made by monitors)

J. ARC-Ohio will make and send copy to providers within thirty days of visit with cover letter (addendum). ARC-Ohio will take appropriate actions to assure care/safety of individuals if inadequacies are found in homes.

APPENDIX G

OUTLINE OF MONITORING REPORT
(See Appendix H for Sample Report)

I. Cover Page

II. Basic Information Sheet

III. Body of Report

A. Overview of Residence and Visit

B. Basic Reactions of Monitors

C. Rights

1. Strengths
2. Weaknesses
3. Recommendations

D. Commitment to Personal Growth

1. Strengths
2. Weaknesses
3. Recommendations

E. Staff

1. Strengths
2. Weaknesses
3. Recommendations

F. Environment

1. Strengths
2. Weaknesses
3. Recommendations

G. Use of Community Resources

1. Strengths
2. Weaknesses
3. Recommendations